



1 December 2014

New Zealand Productivity Commission
PO Box 8036
The Terrace
Wellington 6143

MORE EFFECTIVE SOCIAL SERVICES

Thank you for the opportunity to provide comment on the Issues Paper *More Effective Social Services*.

Alzheimers New Zealand – and response to this important issues paper

Alzheimers New Zealand (www.alzheimers.org.nz) represents people affected by dementia at a national level by raising awareness of dementia, providing information and resources for people affected by dementia, advocating for high quality services for people affected by dementia, and promoting research about prevention, treatment, cure and care of people affected by dementia.

We also support a federation of 21 local Alzheimers NZ organisations throughout New Zealand, each of which is a member of Alzheimers NZ. Our local Alzheimers organisations provide support and personal advocacy, education, information and related services directly to members of their communities who are affected by dementia.

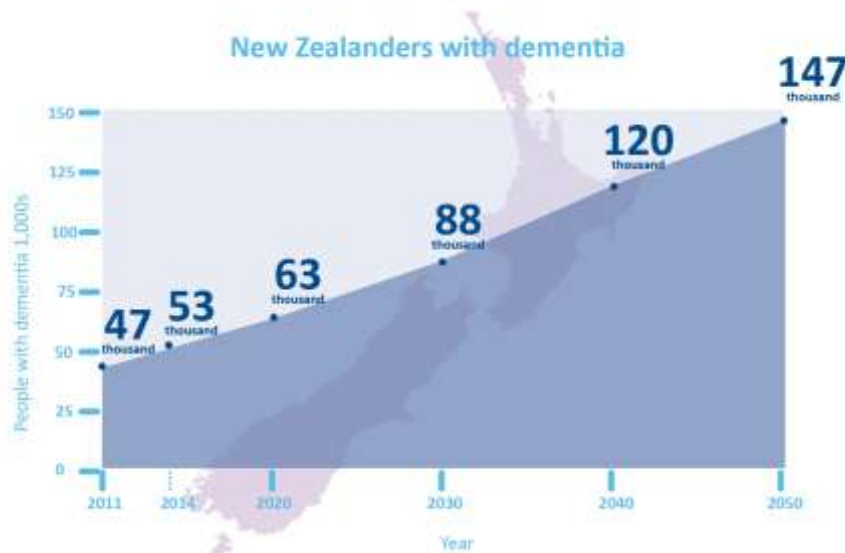
Our comments below are largely descriptive in nature and are limited to the questions that we view as the central 'issues' in relation to people affected by dementia; we do not purport to have developed solutions to the various issues in social service provision in New Zealand. We do however, strongly support the Productivity Commission's focus on this issue. The next steps in the Commission's approach will also dovetail well with what Alzheimers NZ is promoting as an urgently needed 'national discussion' on dementia involving the wider dementia community (government, private providers and community organisations – **and** people with and affected by dementia) to determine a comprehensive approach for providing a consistently high-quality response to the challenge that is dementia.

Question 1: The Impact of Dementia – Changing the Social Services Landscape

Dementia is one of New Zealand's most significant and growing healthcare challenges, which already has a significant impact on families, on our communities, on the healthcare system and on our economy; as a result of the growth in the number of people affected, dementia will change the social services landscape in New Zealand.



Alzheimers NZ estimates that there are currently 50,000 New Zealanders living with dementia and we expect that number to triple to 150,000 by 2050 as the population ages.¹ And that is just the tip of the iceberg; each person with dementia is surrounded by family/whānau and friends who are also affected by their diagnosis.



Alzheimers NZ recently conducted a benchmarking survey,² which demonstrates just how widespread the impact of dementia is – two out of every three New Zealanders know or have known someone with dementia – and for many New Zealanders, dementia directly affects their family/whānau and daily lives.

The Ministry of Health also notes that “there are large health and social costs for the person with dementia, including lost quality of life, a shortened lifespan, and the impact their condition has on their family/whānau and friends”.³ The Ministry has also noted that dementia is one of the top four leading causes of health loss for people aged over 75 years.⁴

The impact of dementia on health care services is also significant. We know it is likely that only around half of the people with dementia currently have a diagnosis⁵ and that even fewer people are accessing and receiving support through the services that are available. And even now, support services are struggling to meet the need. Further, the 2013 World Alzheimer’s Report *Journey of Caring: an analysis of long term care for dementia* tells us that long-term residential care (whether in dementia-specific services or general services providing care for the elderly) is mainly about care for people with dementia.

¹ *The Dementia Economic Impact Report*, prepared by Deloitte Access Economics for Alzheimers NZ (2012).

² *Awareness and Understanding of Dementia in NZ*, Alzheimers NZ (2014).

³ *Improving the Lives of People with Dementia*, Ministry of Health (2014).

⁴ *Health Loss in New Zealand*, Ministry of Health (2013).

⁵ *The Benefit of Early Diagnosis and Intervention*, World Alzheimer Report 2011, Alzheimer’s Disease International (2011).



Dementia also has a significant impact on the economy. The Dementia Economic Impact Report suggested the cost of dementia to New Zealand in 2011 was almost \$1b, reflecting the direct costs of medical care, the direct costs of social care, and the indirect costs of the care and support provided by family/whānau. That cost will already be greater today and is set to increase significantly as the number of people with dementia increases.

Question 2: The Role of Volunteers

Support for people affected by dementia who live at home and as part of our communities (rather than in residential care) relies on voluntary work – largely provided by family/whānau, with support from community organisations and other providers who also rely heavily on volunteer input.

Family/whānau remain under pressure – and the current eligibility arrangements mean they often struggle financially and face complex and repeated hurdles.

In Alzheimers NZ's view, this reliance on volunteers is to a level well beyond what is fair or appropriate – and potentially beyond what is sustainable as the number of people affected by dementia increases.

Question 10: Innovations in Commissioning and Contracting

The current health-based contracting arrangements are a volume-based one size fits all model that discourages innovation, flexibility and risk taking. The strategy, purchasing and administrative arrangements are also replicated 20 times (through each District Health Board (DHB)) and nationally across the various public service departments. And with those fragmented arrangements comes risks (and actual) unplanned inconsistencies in approach that negatively impact the consistency and quality of services that people affected by dementia are able to access.

Some efforts are underway to address some of these issues. To date though, new arrangements have been limited in number and scope, and do not yet extend into the way that DHBs purchase services from community-based organisations. As these new arrangements are further developed and implemented more widely, lessons can be drawn from:

- the Whānau Ora approach, in particular the focus on putting the family/whānau at the centre of the system;
- the move to relational contracting, in particular the way this model of contracting places value on both players in the relationship – tailoring to suit the particular requirements of the contract for both parties;
- outcome based contracting that shifts the focus to the difference being made;
- client-directed budgets such as those that apply in the disability sector; and
- the recent changes in financial reporting in the social profit sector that recognise the significance of size and scale, tailoring requirements accordingly.



Another factor to be considered is the link between the contracting model and service delivery model – the needs assessment and service coordination arrangements for older people act in many ways as a brokerage role and the new Navigator role (established under the New Zealand Framework for Dementia Care (2013)) is also likely to cross-over into purchasing at an individual level. Implementation of this role however, is not yet underway across DHBs.

Question 13 and 14: Improving Service Integration

New Zealand is too small for the level of disaggregation that currently exists in the funding, purchasing, administration and delivery of services for people living with dementia. The current arrangements cause, or allow unchallenged, inconsistent service delivery – both in terms of the type and volume of services available and the quality of those services. Services are inconsistent between DHBs and across client groups – and there is very little collaboration or integration in provision at either a private or community-organisation level.

A simple ‘solution’ is to move to more centrally purchased health and related social services, in particular the core services on which people living with dementia rely. More central provision may also support use of joint contracting involving more than one community organisation in order to secure a greater specific focus on, in terms of our purpose, supporting people affected by dementia.

Question 21: Flexible Service Delivery and Government Accountability

Social profit organisations such as the local organisations that are Alzheimers NZ Members are part of the core service delivery model, fully linked into the new dementia care pathways being implemented by Government through DHBs. Even so, contracts with DHBs at best part fund services. The current arrangements to support people living with dementia rely on our Members and other social profit agencies subsidising Government through the work provided by their volunteers, or otherwise paid for through their fundraising efforts (street appeals etc) and the time and labour intensive process of applying for grants every year. In addition to the subsidisation, this reality for all community-based social profit organisations generally means that they are unable to make meaningful investment in changing or improving the quality of their services.

New government policies – such as the shift to early detection of dementia – are implemented without acknowledgement or even recognition of the impact on providers, such as our Members, who are left to raise additional funds to respond to the increase in demand. At the same time DHBs and other Government agencies seek greater specificity and reporting in the name of accountability – thereby unnecessarily increasing compliance costs, especially as the greater specificity generally relates to input and process matters, with little real focus on service quality or outcomes for people affected by dementia.

Overall the current model asks the social profit sector for high levels of accountability in the name of efficiency and flexibility, requiring greater levels of detail than the comparable requirements that those agencies themselves face – with uncertain value.



The current model also reinforces the tension between local and national services (and providers). Different arguments support each mode of delivery but if people living with dementia are to have confidence in consistently high quality services, purchasing arrangements must reduce the frequency of small contracts to achieve greater consistency in approach and effect across the country.

Question 22 Relational Contracting

High trust contracts rely on a sense of mutual value in the relationship and high levels of professional judgement, supported by strong outcome measures and reporting. The current purchasing model for services for people living with dementia is based on low cost and easy to count/capture aspects.

A shift to relational contracting would require significant investment in the development of outcome measures to be used across service providers and in relation to different health or social matters, together with the professional capability required to develop and manage the necessary relationships.

A specific issue of concern to Alzheimers NZ is that the data vacuum relating to dementia needs be addressed, including arrangements for the systemic collection of data through a common data set. A national approach to managing this, which does not need to rest with a government agency such as the Ministry of Health, would give the work direction and simplify the process.

Question 24 Dependent Relationships

At an individual level the relationship with the provider and the consistency of the services are paramount. Achieving a balance between these requirements and the opportunity for better value (price and quality) by opening up for contestable processes will always be a challenge. Population density also limits opportunities for effective contestability everywhere except Auckland.

Nevertheless, the current arrangements create a situation where Government agencies are too dependent on DHBs, who because they combine the purchaser and provider roles have an inherent conflict of interest in the purchasing decisions they make, and may not look more widely even when there is capacity and capability in the sector – examples would be of this situation include the choices DHBs have made to deliver the *Walking in Another's Shoes* programme and establish the new Navigator role.

Equally, social profit agencies are often too dependent on their contracts with DHBs and focus their service delivery to match those contracts rather than necessarily what they know to be greater need in their communities. A similar though less specific dynamic occurs in the relationship between community organisations that focus on grants from agencies such as Lotteries and Pub Charity, where the funding organisations set preferred areas for directing the funds they distribute.

The dementia sector is and is likely to remain small so it is likely to be difficult to avoid dependent purchasing/funding relationships entirely. What would help however, is a more transparent funding and purchasing model and funding decisions with a longer time horizon (two to three years).



Thank you for the opportunity to provide comment on the Issues Paper *More Effective Social Services*. We would welcome the opportunity to discuss the issues raised in this submission with you, and to remain involved in and contribute to your deliberations as you progress this work.

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